## **HIV/AIDS** and African American Women:

A Consultation Supporting CDC's Heightened National Response to the HIV/AIDS Crisis among African Americans

**Meeting Report** 

## U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Disease Control and Prevention
National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention
Division of HIV/AIDS Prevention
2007

## **About This Report**

This report summarizes a consultation which focused on HIV/AIDS among African American women. The consultation held June 20–21, 2007, in Atlanta, Georgia, was organized by the Prevention Partnership Office within the Division of HIV/AIDS Prevention at the Centers for Disease Control and Prevention. This report is available at http://www.cdc.gov/hiv/topics/aa. Members of the public and stakeholders are invited to read the document and submit their views via hnr@cdc.gov. The public's feedback on the suggestions presented in this report will be useful in formulating new strategies to address the HIV/AIDS crisis affecting African American women.

## **Suggested Citation**

Centers for Disease Control and Prevention. *HIV/AIDS and African American Women: A Consultation Supporting CDC's Heightened National Response to the HIV/AIDS Crisis Among African Americans. Meeting Report.* Atlanta, Georgia: Centers for Disease Control and Prevention, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Division of HIV/AIDS Prevention, 2007.

# **Contents**

| Executive Summary                        | 3  |
|--|----|
| Meeting Report                           |    |
| Background                               |    |
| Meeting Goals and Objectives             | 6  |
| Process                                  | 7  |
| Participant Observations                 | 8  |
| Discussion Matrix                        |    |
| References                               |    |
| Additional Resources                     | 16 |
| Appendices                               |    |
| Appendix A – Final Participant Directory | 17 |
| Appendix B – Agenda                      |    |

## **Executive Summary**

Women of color are especially affected by HIV infection and AIDS. African American women make up only 12% of the female population in the United States, yet they account for 66% of new HIV infections. In 2004, HIV infection was the leading cause of death for African American women aged 25–34 years and the third leading cause of death for African American women aged 35–44 years. In 2005, the rate of AIDS diagnoses for African American women was 20 times the rate for White women. HIV/AIDS-related conditions are now the leading cause of death for African American women aged 25-34 years. The reasons for increased AIDS incidence and deaths among African American women are complex.

To develop comprehensive strategies to reach African American women most in need, the Centers for Disease Control and Prevention's Division of HIV/AIDS Prevention held a meeting in June 2007 titled HIV/AIDS and African American Women: A Consultation Supporting CDC's Heightened National Response to the HIV/AIDS Crisis Among African Americans. This consultation was guided by four main areas of focus: 1) expanding the reach for prevention services, 2) increasing opportunities for diagnosing and treating HIV, 3) developing new, effective prevention interventions, and 4) mobilizing broader community action. These areas had been identified earlier in the CDC action plan titled A Heightened National Response to the HIV/AIDS Crisis among African Americans.

The consultation gave participants the opportunity to share their collective knowledge and skills and generate suggestions for HIV prevention strategies for underserved African American women most affected by HIV/AIDS. Meeting participants identified a number of cross-cutting issues in African American women's lives that places these women at risk for HIV; the participants questioned what can be done to give young African American women the skills they need to reduce risk; and participants provided suggestions on how public health agencies and a range of community-based and stakeholder organizations could assess and manage the HIV/AIDS crisis among African American women.

### HIV/AIDS and African American Women:

A Consultation Supporting CDC's Heightened National Response to the HIV/AIDS Crisis among African Americans

## **Meeting Report**

### **Background**

New HIV infections and HIV/AIDS-related deaths disproportionately affect African American women (1, 2), despite advances in HIV treatment and declines in HIV infections among other risk groups. Women of color are especially affected by HIV infection and AIDS. African American women make up only 12% of the female population in the United States, yet they account for 66% of new HIV infections (6). In 2004, HIV infection was the leading cause of death for African American women aged 25–34 years and the 3rd leading cause of death for African American women aged 35–44 years (3). In 2005, the rate of AIDS diagnoses for African American women was 20 times the rate for White women (6). HIV/AIDS-related conditions are now the leading cause of death for African American women aged 25-34 years (7).

Recent CDC data show that the main risk factors for most HIV/AIDS diagnoses among African Americans females are high-risk heterosexual contact (80%) followed by injection drug use (18%); and as with all racial and ethnic groups, African Americans at higher risk for HIV are those who are unaware of their partner's risk factors, have other sexually transmitted diseases (STDs), and have unprotected anal and vaginal intercourse (6, 8). Injection drug use is a risk factor for African American women, but it is less of a risk factor for them than for White and Hispanic women. In 2004, an estimated 17% of African American women with AIDS reported that they used injection drugs compared with 31% of White women with AIDS and 21% of Hispanic women with AIDS (9).

The reasons for increased AIDS incidence and deaths among African American women are complex (1, 10). Among the reasons for increased incidence are: There are disproportionately high HIV infection rates among African American women, large numbers of African American women at risk for AIDS, and African American women might benefit less from antiretroviral therapy than other groups because they have greater difficulties with access to care and adherence to treatment than other women (1, 2, 11, 12).

Race and ethnicity, alone, are not risk factors for HIV infection. Poverty and other social and structural influences are associated with higher HIV/AIDS incidence among African Americans (13). African American women at high risk for HIV often sustain the brunt of racism, discrimination, poverty, and sexual abuse. These social determinants may be influencing factors which can contribute to their decreased ability to protect themselves against this devastating disease.

These compelling data demonstrate the need to convene diverse stakeholders in order to discuss, identify, and develop comprehensive strategies to reach African American women most in need.

In March 2007, CDC's Division of HIV/AIDS Prevention announced an action plan to respond to the major health crisis of HIV/AIDS among African Americans. This action plan, titled *A Heightened National Response to the HIV/AIDS Crisis among African Americans*, focuses on four

main areas: 1) expanding the reach for prevention services, 2) increasing opportunities for diagnosing and treating HIV, 3) developing new, effective prevention interventions, and 4) mobilizing broader community action (14). The HIV/AIDS and African American Women Consultation convened by the CDC and held in Atlanta, Georgia on June 20-21, 2007, was guided by these four main areas. The consultation gave participants the opportunity to share their collective knowledge and skills. Participants included stakeholders from academia, state and local health departments, community-based service providers, and others with expertise regarding African American women's historic, cultural, economic and health issues and in serving African American women (for a list of participants, see Appendix A). Most importantly, the consultation generated ideas and thoughts for prevention strategies to better meet the needs of underserved African American women affected by HIV/AIDS.

#### **Meeting Goals and Objectives**

The overarching goals of the consultation were to identify possible HIV prevention strategies for underserved African American women most affected by HIV/AIDS and to develop strategies aligned with the *Heightened National Response* action strategies that would address the HIV/AIDS crisis among African American women. To achieve those goals, participants aimed to meet the stated objectives within each of the following four focus areas outlined in the CDC action plan:

#### Focus Area 1. Expanding the reach for prevention services

*Objective:* To identify strategies to expand prevention services for African American women at risk for HIV/AIDS.

## Focus Area 2. Increasing opportunities for diagnosing and treating HIV

*Objective:* To increase African American women's knowledge of HIV status and linkages to treatment.

#### Focus Area 3. Developing new, effective prevention interventions

*Objective:* To increase research on effective ways to reduce risk behaviors that lead to HIV infection in African American women.

#### Focus Area 4. Mobilizing broader community action

*Objective:* To increase community action for greater awareness, communication, and HIV testing for African American women.

#### **Process**

Individuals were invited to participate in the consultation after they had been identified and recommended by stakeholder groups, professional organizations, and CDC staff.

Dr. Kevin Fenton, Ms. Janet Cleveland, and Dr. George Roberts addressed the participants and provided overviews and updates on the HIV/AIDS crisis among African American women, CDC's *Heightened National Response* action strategies, and the vision for CDC's overall response to the crisis and outcomes of programmatic efforts. In addition, the following individuals addressed the participants and provided information on the epidemiological, social, economic, and co-morbidity factors associated with the HIV/AIDS crisis among African American women:

Dr. Madeline Sutton, Division of HIV/AIDS Prevention, CDC

"The HIV/AIDS Epidemic and Black Americans"

Dr. Monica Sweeny, New York City Department of Health and Mental Hygiene

"Social issues and Economic Factors of the Epidemic"

Mr. David Johnson, Division of STD Prevention, CDC

"Can You Hear Me Now? Linking STIs and HIV infection"

Ms. Hope King, Division of Viral Hepatitis, CDC

"Viral Hepatitis Prevention: Overview & Integration Projects"

Ms. Danni Lentine, Division of HIV/AIDS Prevention, CDC

"Triple Stigma: Race, HIV, and Drug Use"

Dr. Nick DeLuca, Division of TB Prevention, CDC

"Stop TB in the African-American Community"

Ms. Frances Ashe-Goins, Office of Women's Health, U.S. Department of Health and Human Services

"The Model Mentorship Program for Strengthening Organizational Capacity"

Meeting participants were assigned to four groups, each addressing a different focus area from the *Heightened National Response* action strategies. They then discussed the key factors contributing to the HIV/AIDS crisis among African American women and systematically identified and categorized areas for consideration and suggested priorities for their focus area (for a detailed summary of their discussions, see the Discussion Matrix beginning on page 10).

Participants were asked to address the following questions for their focus group:

#### Focus Area 1. Expanding the reach for prevention services

• What can be done to ensure that African American women receive appropriate and effective prevention services?

#### Focus Area 2. Increasing opportunities for diagnosing and treating HIV

- How we can increase the numbers of African American women who receive HIV testing?
- What can be done to make sure that HIV-infected African American women are linked to effective prevention, treatment and care services?

Focus Area 3. Developing new, effective prevention interventions

- What additional research questions and strategies should be considered in developing effective interventions for African American women?
- How can community-based service providers contribute to the development of effective risk-reduction interventions for African American women?

#### Focus Area 4. Mobilizing broader community action

- How can we increase community support for HIV testing, diagnosis, and treatment?
- What is the role of African American women's organizations in addressing the HIV prevention needs of African American women?

In accordance with Dr. Fenton's charge to the group to consider co-factors, co-morbidities, and the need to consolidate prevention efforts and strategies, the meeting agenda was modified to facilitate a large group discussion to identify and recommend salient strategies for addressing the HIV/AIDS crisis among African American women across a broad spectrum (for the complete meeting agenda, see Appendix B). The following question was asked of the larger group:

• What are the co-morbidities for HIV and how do they affect African American women?

#### **Participant Observations**

Participants identified current activities, some of which supported by the CDC that are now in place to help African American women (for a summary of participant identified *Current Activities*, see the Discussion Matrix, page 11). Participants also developed a list of areas for consideration, which are activities that could be undertaken to address HIV/AIDS among African American women. For example, participants suggested that HIV prevention activities could be integrated into services provided by women's organizations; and, that HIV tests could be done when women come in for their annual Pap tests, that more qualitative studies are needed to develop new interventions, and that educational classes should be offered to teach parents how to talk to their children about sex (for a summary of *Areas for Consideration*, see the Discussion Matrix, page 11).

When asked to provide suggestions and identify priorities, the participants contributed many. The participants developed more than 60 suggestions and priority actions reflecting their extensive knowledge and experiences. For example, participants suggested that differences in urban vs. rural implications for HIV/AIDS services must be studied, try new ways to deliver messages about HIV risk that do not focus on the stigma associated with the source of infection, identify what drives behavior, and mobilize women with HIV to teach other women about prevention (for a summary of all *Suggested Priorities*, see the Discussion Matrix, page 12).

After identifying current activities, areas for consideration, and suggested priorities, participants began to draft other suggestions to reduce the burden of HIV/AIDS among African American women. These observations provide suggestions on how to prevent transmission of infection and provide details on the specific framework within which regulatory bodies, local public health agencies, and a range of community-based and stakeholder organizations could assess and manage the HIV/AIDS crisis among African American women (for a summary of all *Other Participant Suggestions*, see the Discussion Matrix, page 13).

While it can not be guaranteed that all participant suggestions will be implemented, the cross-cutting issues and observations provided by the participant during discussion of co-morbidities for HIV and

how do they affect African American women s provides the CDC with valuable insight of what may need to be considered when strengthening public health efforts to reduce HIV/AIDS among African American women (for a summary of *Participant Issues and Observations*, see the Discussion Matrix, page 14). Some of the participant suggestions are complex and must be corroborated by a systematic review of the literature, and phase-in time will be needed to allow efficient, effective implementation and evaluation of these activities. However, by involving members of the community and following the key areas identified in the *Heightened National Response* action strategies, we can make strides toward reducing the high rates of HIV/AIDS among African American women.

#### Discussion Matrix HIV/AIDS and African American Women: A Consultation Supporting CDC's Heightened National Response to the HIV/AIDS Crisis among African Americans — June 20-21, 2007, Atlanta, Georgia Focus Area 4. Focus Area 1. Focus Area 2. Focus Area 3. Expanding the reach **Increasing opportunities** Developing new, Mobilizing broader for prevention services for diagnosing and effective prevention community action treating HIV interventions Sisters Informing Sisters on Outreach (HERR, after-6-week educational series **Current Activities** Mass testing events, and the Topic of AIDS (SISTA) (Note: Some of these activities are school programs) church community and about HIV for newly currently supported by the CDC.) college testing modifications to educate diagnosed African both HIV-infected and American women HIV-negative Social support services Mass media SISTA modifications for Prenatal care activities (i.e. housing, food, commercial sex workers communications and incarcerated women transportation) Testing, treatment, and Call-in roundtable Why Women Cry Observance days discussions Conference care (accessibility and availability) Seeking political advocacy National program focusing **Encourage Women Living** Support groups (tailoring to population) on men talking to women with HIV to provide HIV ("I take responsibility for info to incarcerated the women in my life") women Ryan White Title 4 UCHAPS social marketing Partner services Diverse funders supporting HIV campaign Social Network Model Prevention for African American women Normalized testing for **Reaching Out Sisters Educating Sisters** pregnant women (ROSES) Celebrating Your Rapid testing **Tomorrows** Connected testing with Faith-Based Health Day other STDs The Living Room, The Bedroom and The Den

|                         | Focus Area 1. Expanding the reach for prevention service   | Focus Area 2. Increasing opportunities for diagnosing and treating HIV   | Focus Area 3. Developing new, effective prevention interventions                         | Focus Area 4. Mobilizing broader community action                                   |
|-------------------------|--|--|--|---|
| Areas for Consideration | Redefine risk (i.e., individual vs. structural, alternative construction, cultural competence)   | Reinstitutionalize peer health<br>advocacy and support<br>programs for women   | Seek input from the target audience  | Develop new HIV prevention curriculum for grade schools                             |
|                         | Involve youth and create more opportunities for meaningful input to improve communication re: HIV risk "Knowledge does not equal behavior change." | Check to determine if states<br>are supportive in preventing<br>and treating HIV, and develop<br>report card on various<br>indicators; encourage national<br>health care | Conduct qualitative studies  | Create new HIV prevention<br>messages for African<br>American women                 |
|                         | Improve understanding of male partner behavior   | Expedite data collection and dissemination   | Connect issues outside of HIV that affect HIV  | Create programs that include<br>gender risk awareness for<br>African American women |
|                         | Broaden discussions about risk and sex   | Prison testing and support   | Structural and behavioral interventions  | Educational classes to help parents talk to kids about sex                          |
|                         | Assess resilience  | Preventive education and support of young people   | Kaffe Klatsch discussions<br>Positive messages ("Protect<br>yourself, respect yourself") | Activities focusing on young girls  |
|                         | Interventions aimed at mixed gender  | Offer HIV testing when<br>women come for Pap tests;<br>test new babies for HIV;<br>emergency room testing  | Mental health in the Black community   | Research on female condoms and microbicides   |
|                         | Comprehensive human growth and development for girls   | Offer mental health services<br>and therapy for women who<br>are newly HIV-infected  | Recognize relationships  |   |
|                         | Reduce stigma to improve perception of risk  | Educate providers on importance of HIV testing   | Healthy discussions around sexuality   |   |
|                         | Integrate HIV prevention in all women service organizations  |  | Intervention that helps men and women discuss sexuality                                  |   |
|                         | Address structural risk factors in Requests for Applications (RFAs) Involve faith communities  |  |  |   |

|                                  | Focus Area 1. Expanding the reach for prevention services              | Focus Area 2. Increasing opportunities for diagnosing and treating HIV                                       | Focus Area 3. Developing new, effective prevention interventions                            | Focus Area 4. Mobilizing broader community action                          |
|----------------------------------|--|--|---|--|
| Participant Suggested Priorities | Sustainability of funds  | Testing events for young people; finding HIV-infected people and those at highest risk                       | Identifying what is driving the<br>behavior (Biggest fear is<br>imminent death)             | Linking HIV prevention<br>services to mental health and<br>substance abuse |
|                                  | Redefining risk for HIV  | Redefining "high risk"   | Providers offering insight, entry into the community  | Expanding HIV prevention<br>messages to African<br>American women          |
|                                  | Tailoring outreach services  | Designing a new framework<br>for delivering messages about<br>risk, without stigma on source<br>of infection | Identifying population to be reached Identifying the intervention.                          | Diversifying resources to support new activities                           |
|                                  | Increasing youth involvement/church programs                           | Increasing awareness of psychological risk factors   | Taking harm reduction approach  | Creating more sustainable funding  |
|                                  | Increasing understanding of urban vs. rural implications for services  | Making treatment attractive  | Professionally analyzing community-based data already being collected                       | Mobilizing women living w/HIV to teach other women                         |
|                                  | Community-based organization (CBO) partnership and evaluation capacity | Involving HIV-infected people in decisions   | Community-based providers include CBOs, elected officials, ministers, other gatekeepers.    | Flexible funding with more integrative approach                            |
|                                  | Dissemination of lessons learned                                       | Increasing awareness of children with AIDS who are now in college  | Responding to social isolation, protect anonymity; still give women an opportunity to talk. | Targeting new money from new partners                                      |
|                                  |  | Educating people to ask for testing  |   |  |
|                                  |  | Substance abuse treatment  |   |  |

|                               | Focus Area 1. Expanding the reach for prevention services  | Focus Area 2. Increasing opportunities for diagnosing and treating HIV                | Focus Area 3. Developing new, effective prevention interventions   | Focus Area 4. Mobilizing broader community action   |
|-------------------------------|--|---|--|---|
| Other Participant Suggestions | Sustain funds to ensure level of service   | Ensure funding is proportionate to need   | Support community-based organizations  | Design Interventions to<br>support prevention messages<br>that work after 5pm             |
|                               | Conduct research to redefine risks (structural factors, "alternative construction," African American women are not monolithic, partner behavior) | Conduct needs assessment to look at what has been done and what needs to be addressed | Develop online registry of community-based organization interventions that are known to work   | Recognize impact of Class<br>Issues on African American<br>Women                          |
|                               | Increase comprehensive youth involvement in design and delivery of services  | Ensure higher level accountability  | Move beyond behavioral<br>interventions – Diffuse<br>Effective Structural<br>Interventions (DESI)  | Create HIV prevention curricula for diverse groups  |
|                               | Conduct research to increase understanding of urban vs. rural implications for prevention services (community norms)                             | Improve AIDS education in school, including prevention and treatment                  | Develop tools that can be used<br>in different environments and<br>locations to get good, rich data<br>around behaviors and<br>interventions                 | Include the needs of substance users and street workers                                   |
|                               | Assess individual level resilience ("How do some youth make it out [i.e., not get infected?]")   | Educate providers that STI testing should be integrated into total care               | Educate healthcare providers Develop national, wholesale, widespread marketing program Build capacity to increase acceptance of good homegrown interventions | Reevaluate the needs of<br>women who have sex with<br>women and lesbians                  |
|                               | Support locally tailored outreach services   | Address structural barriers — transportation, childcare, etc.                         | Community involvement from beginning to end, equal partners drive research questions   | Provide funding without taking money from existing programs                               |
|                               | Develop CBO evaluation capacity to improve reporting of successes and RFA development  | Develop new HIV tests — surgical swabs, dental testing, etc.                          | Develop comprehensive<br>systematic research agenda for<br>and about Black women   | Recognize need for cross-<br>community interventions                                      |
|                               | Develop national campaign for women and girls  | Ensure compassionate care for marginalized black women                                | Identify African American researchers who have perhaps not been heard  | Support programs that do not have a direct focus on HIV but can effect reduction of risk. |